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The National
Autistic Society

harc HERTFORDSHIRE BRANCH

JUNE 2007 Newsletter

harc & NAS news

Funding for the Adult Social Group

As many of you will know harc are currently working with the Community Learning Disability Team (CLDT) to provide a social group for adults with Asperger's/High Functioning Autism. This is a pilot project involving close partnership working between harc and CLDT and is based in St Albans led by a Community Learning Disability nurse, Alison Carpenter.

harc has been involved in the project from the outset. We have provided the initial start up costs, produced the promotional material, widely publicised the group and are now undertaking to find speakers to come in and speak to the group on many different topics such as financial management, healthy living, employment and training and personal safety. We currently have a group of about ten people regularly attending. We recently applied to the Hertfordshire Community Foundation for a grant to enable the group to continue. We are delighted to announce that we have now received a grant of £2500. This will secure the future of the group for an additional nine months.

Adult Care Services have also said that they will provide £5000 to harc to extend the group and to pay volunteers to help to run the group. This is a hugely important step forward as it does secure the group for about 18 months and will give us an opportunity to measure the impact of the Group and as a result to work with ACS to replicate this facility around the county.

If you know of anyone who may be interested in attending please contact Alison Carpenter either by email Alison.carpenter@hertscc.gov.uk or phone 01442 454444 or fax their name and telephone number to 01442 454422

harc are grateful to Hertfordshire Community Foundation for their support of this project.
Ann Griffin - harc member

Launch of new local ASD support group in Welwyn/Hatfield area. Monday 16th July

This group is being launched by harc member Lesley Zorlakki, supported by harc at Oak Tree Children's Centre, Holwell Rd, Welwyn Garden City. The launch meeting is from 7.30 to 9.30pm and is open to all harc members and also parents/carers and grandparents of children with an autistic spectrum disorder in the Welwyn and Hatfield area. It is envisaged that the group will meet on the 3rd Monday of each month during term-time and will be a mixture of informal get-togethers and invited speakers. This will not replace the larger harc meetings and is in response to local needs/requests.

Please come along and support harc in this new venture. For further information contact Lesley Zorlakki on 0771 448 3485 or Zorlakki@onetel.net

Launch of Girls 'Aspie' Social Group

The first social of this new group will be on Tuesday 31st July 2007 from 10am to 12 noon at Arts4fun, 172 West End Lane, West Hampstead,

London NW6 1SD. Located close to West Hampstead tube, Silverlink & Thameslink. There will be a picnic in the local park afterwards - if dry!
Places are £5 and can be booked by contacting Lesley Zorlakki on 0771 448 3485 or email Zorlakki@onetel.net

**Five day training for Carers of adults:
Understanding Autism and Asperger's (ASC)**
Mark Dixon, chair of the Hertfordshire Asperger Working Group was tasked to provide training for staff across the county and given a budget of £100,000. He has engaged Prime Performance Solutions to provide the training for staff in Herts County Council and Herts Partnership NHS Trust staff in understanding autism. There are two levels of training: one is aimed at those who work on the front line, for instance social workers, the other at clinicians and managers. The training for front line staff has been designed to provide new strategies and techniques to compliment their skills and abilities.
Mark has recognised the role that carers play in looking after adults with autism and has asked Prime Performance to devise training suitable for carers to attend. The five consecutive days will cover:
Autistic Spectrum Conditions; core symptoms, sensory issues (including clothing), diet, special interests, impact on the individual, their family and their environment, case studies and problem solving.
Related conditions and their impact on ASC: ADHD, OCD, Anxiety & depression.
Special Needs:
Sleep, identity & independence, sexuality, preparing for adulthood, attending college.
Relevance of label:
Outcome without a diagnosis, importance of the family.
Medication and alternative treatments.
Coaching - what it is, how it works and the difference between coaching, mentoring and therapy.
Communication & behaviour

Behavioural interventions & coaching tools.
The course will run for five whole consecutive days from 19th to 23rd November. Mark is offering 10 free places to carers. If you would like to find out more or put your name forward for one of these places please contact Mark by telephone 01442 454444 or email: mark.dixon@hertscc.gov.uk

Parent to Parent Services
Parent to Parent is a national confidential freephone support service offered to parents or carers of an adult or child on the autistic spectrum. Callers can access the service by dialling 0800 9 520 520, more information can be found at www.nas.org.uk/p2p. The service is provided by volunteer parents who themselves have a child or adult on the autistic spectrum. Parents or carers can phone the freephone number and leave a message on the 24 hour ansaphone. You will then be contacted by a trained parent volunteer, at a convenient time, who will provide the opportunity for parents to talk through issues, feelings and problems.
This is a free and confidential service provided by parents for parents.
The Parent to Parent Line is part of the Volunteering Network. The NAS are currently trying to recruit more volunteers in the London area with the training taking place in early July. If you would like to volunteer please contact Nicola Rae (Parent to Parent Service Coordinator) on 0115 8473516.

Transition Information Network
My Future Choices is a magazine produced by the Transition Information Network (TIN). The TIN is an alliance of organisations and individuals who have come together with the common aim to improve the experience of disabled young people's transition to adulthood. The National Autistic Society is a member of this alliance. The TIN provides a number of resources to young people with a disability who are going through transition and to their parents and professionals. For more information or to register to receive a copy of the

magazine see their website on

www.myfuturechoices.org.uk

NAS Summer Raffle - help support your branch

Help fundraise for your branch by selling some of the special books of raffle tickets for the NAS summer raffle. The first prize is £1000 with a £40 M&S voucher for the individual supporter who sells the most tickets. 30% of the surplus (after costs) of any tickets sold by the branch will be given to the branch for us to use on local projects. If you would like tickets to sell then contact the Branch Officer, Laurence Griffin by email Laurence.griffin@ntlworld.com or phone 01707 895467

Need a phone number? Fundraise for autism.

If you need directory enquiries then by calling Talk Talk 118 111 Directory Enquiries at 35p a call, one penny from each call goes to TreeHouse the national charity for autism education.

www.treehouse.org.uk

Online petitions for the new Prime Minister - sign up to support change for ASD.

These are two of the petitions on the PM's website that HARC hopes you will sign up to.

Petition 1 - We the undersigned petition the Prime Minister to increase support services in the UK for people with Asperger Syndrome and other Autistic Spectrum Conditions, their families, schools and employers

<http://petitions.pm.gov.uk/aspergersupport/#detail>

Petition 2 - We the undersigned petition the Prime Minister to undertake a major review of the Special Educational Needs policy as recommended by the House of Commons Education and Skills Committee and make provision for a system of special educational needs that is fit for purpose.

Deadline to sign up 24th July

<http://petitions.pm.gov.uk/FitForPurposeSEN/>

Useful articles available.

The following articles published in Communication magazine may be of interest to members, contact the HARC office for a copy

1. Telling a child about their Asperger Syndrome
2. Fluff and stuff - pica (eating non-food stuff).
3. Dietary interventions.

Money to make a difference

Is there a piece of equipment, communication aid or a particular service that you think will benefit your disabled child and which your local authority will not fund?

Are you having difficulties paying for it?

Does it cost less than £2,000?

Can you find a professional to back up your claim?

If your answer to all these questions is yes, the Council for Disabled Children may be able to help.

Contact them at: Council for Disabled Children, 8 Wakley St, London EC1V 7QE Tel: 0207 843 1900

www.ncb.org.uk/cdc

Education

CSF's new funding arrangements for SEN in Herts schools

As many of you are already aware CSF brought in a new funding system for SEN in its schools in April 2007. Most of the funding is now devolved to schools and ear marked pupil funding has gone.

We are very keen to get feedback from members on how this is working in practice. Have things improved or worsened for your child in school or there is no difference?

If you have applied for a statement of SEN how have you got on at any stage of the process? It is very important that we get this feedback if we are to represent the views of parents/carers to CSF education.

Please let us know by email or phone to the HARC office or to Paul Phillips our treasurer.

Please remember that we have details of various independent organisations who offer advice on SEN issues and statementing. Please contact the office for details.

Useful articles

We have 2 articles from Network 81 that may be of interest to some of you.

The first one is an Information Sheet with guidelines on writing the parental advice for the statutory assessment process.

The second one is a Parents Guide to P Levels and PIVATS. These are used to show the progress of pupils working below Levels 1 or 2 of the National Curriculum

Contact the Harc office if you would like a copy.
Source: Network News, Network 81.

SEN survey by National Autistic Society

The NAS policy team has developed a survey on improving the SEN system in England and Wales. They would like as many people as possible to contribute their ideas to this survey it can be accessed at www.autism.org.uk/sensurvey

This is part of the make school make sense campaign.

Web discussion link: getting education help?

The BBC website has a discussion on 'What's your experience of getting children the education help they need?' This discussion follows comments on the radio by Lord Adonis that suggest he is entirely out of touch with the experience of parents! Read a wide variety of comments about SEN provision, not just from parents, but also from people working with SEN children in other sectors

www.bbc.co.uk/blog/pm/2007/05/children_with_special_needs.shtml

Source: Umbrella eNews May 07

Is your child in an out of county school?

These are schools not run or financed directly by HCC. The Audit Commission recently criticised Local Authorities for failing to check up whether children in out of county schools were making progress or not.

If your child is in an out of county school then when your annual review meeting is due you may well find that a representative from CSF such as an Educational Psychologist is there with the aim of considering whether the placement is still appropriate. Perhaps parents may like to bear this in mind when they write their parental representation for the annual review.

Managing medicines at school

If you have experienced difficulties getting your child's medicine administered while they are at school, you might be interested in obtaining a document published by DfES called *Managing Medicines in Schools and Early Years Settings*. It sets out the responsibilities of parents, teachers, other staff and governing bodies. You can get your own copy by phoning 0845 600 9506 or downloading it free from www.dfes.org.uk (search on managing medicines in schools)

Source: Carewaves

The Further Mathematics Network

This network exists to encourage the further study of mathematics. It may be of interest to those members with young people who have a strong interest or ability in this area and who may not be being stretched at school.

The network is coordinated by Mathematics in Education and Industry www.MEI.org.uk

Can you help with spare toys and games?

Pinewood MLD secondary school in Ware has recently set up an autism base and are looking for resources. Do you have any spare/unwanted toys, puzzles, videos/DVDs or games linked to any of the following TV or film characters?

The Simpsons, Dr Who, Star Wars, Postman Pat, Charlie Chalk, Thomas the tank engine, Toy Story and Bug's Life.

If so and you would be happy to donate them please contact me, Carol Kelsey, on 01707 390319 and I will arrange collection. Many thanks!

Health

CAMHS - an introduction

We have a useful article in the office that gives a basic first guide to what CAMHS is and how it operates, if you would like a copy please contact the office by phone or email.

Source: THE ASC Good Practice Guide

The Open Toy Box - Play therapy practice

The Open Toy Box operates throughout Dacorum, Herts and Bucks. It offers a safe environment, a place of agreed confidentiality, mutual trust and

respect and the focus is on the individual's expression of themselves through the use of talk, play and toys.

The practice offers its services to pre-school children through the age range to adults and private individuals can self refer.

To find out more contact Karla Burley, Play therapist on 07971 486685 or email playtherapy@theopentoybox.co.uk or website www.theopentoybox.co.uk

Shaving and autism

We have a short article in the harc office about tackling the issue of shaving with a severely autistic young man, if this may be of use to you please contact the office and we can send you a copy.

Source: Challenging Behaviour Foundation

Carers needed to help shape Hertfordshire Partnership NHS Trusts' Services

Hertfordshire Partnership NHS Trust is one of the organisations within Herts that provides specialist mental health care. It is looking for carers who have knowledge of the services it provides, in order to involve them more closely in the design, planning and delivery of its services. The Trust is seeking carers of children, adolescents, adults, older people those with drug or alcohol problems and people with a learning disability who also have a learning disability. If you think that you have good ideas about how services can improve and would like to shape mental health services, please contact Jo Burnham, Service User and Carer Involvement Lead on 01727 897761 or joanne.burnham@hpt.nhs.uk

Source: Carewaves.

Social and leisure

New Support Groups:

ADD-Vance has a new support group in Ware for ADHD and Autistic Spectrum. It meets on the 3rd Thursday of each month 7.30pm to 9.30pm at the Family Centre, Park Rd, Ware SG12 0AW
For more information call 01727 833963

ChatSS is a support group for parents/carers of children with a wide range of special needs.

They meet every 3rd Thursday in term time from 1pm to 2.30pm at Hertford Methodist Church (opposite Matalan), Ware Rd, Hertford.

Refreshments are 50p, children welcome, crèche available. For more information contact Angela/Jo via the CHIPS office number 01992 534664 or email chipseastherts@yahoo.co.uk

Carers and the Library service:

Carers, including young carers, can apply for a special card to make it easier to use Hertfordshire library services.

They can borrow up to 24 items for up to 6 weeks (except DVDs). They do not have to pay for overdue charges, reminder letters, music recordings and talking books or reservations on Hertfordshire stock.

To apply for a carer's library card visit your local library or call 01438 737333 (01923 471333 if calling from 0208 or 01923 area codes).

Source: Carewaves

Sense Toys

Set up by Lesley Burton, the mother of an autistic child, the products sold by Sense Toys are well and truly individually 'child tested' in her own home.

The range is suitable for all but particularly for children with SEN, learning disabilities, delayed language development and ASD.

For further information contact them on 0845 2570849 or email: info@sensetoys.com or via their website www.sensetoys.com

Source: HACS newsletter

Sand timers

Many parents find timers invaluable when setting limits for their child with ASD such as how long they can talk about/do their latest obsession.

Sand timers have the visual aspect that our children often need. GLES has sand timers available (www.glsed.co.uk) ranging from 30 seconds up to 30 minutes.

Source: HACS newsletter.

Disabled Children's' Railcard

If your child is in receipt of DLA they can apply for a disabled person's railcard. This cost £14 per year and your child (and the person travelling with

the child holding this card) will be able to get a discount of 33%.

Check the website for more information:

www.disabledpersons-railcard.co.uk

FindaSitter.co.uk

Findasitter is a website that allows parents to find a babysitter. It is not an agency but a directory of sitters - putting you in touch with local babysitters for an annual fee.

They can help families with children with special needs or disabilities.

To find out more email info@findasitter.co.uk or www.findasitter.co.uk

Super Safari - 12th July - Woburn Safari Park

This is a free event for disabled children or those with acute special educational needs. It has been organised by MP Nadine Dorries after she suggested this to the Duke of Bedford. It is from 2pm to 6.30pm on Thursday 12th July.

If you would like more information or would be interested in attending please visit her website for more information www.dorries.org.uk or email at dorriesn@parliament.uk or write to her at the House of Commons, London SW1A 0AA.

Courses and Events

Training for family carers - Understanding the Importance of the Safe Administration of Medication for Carers

Monday July 2nd or Monday July 9th 9.30am to 12.30pm or 1pm to 4pm, Venue: Greenwood Leisure Centre, Chiswell Green, St Albans

Organised by Carers in Herts, the course aims to help carers feel part of the medication administration process and where to get information and advice and how to challenge other professionals and systems.

To book a free place Tel: Carers in Herts on 01442 253 344 or email

west.team@carersinherts.org.uk

Raising Expectations for Children with Special Needs.

Monday 9th July, Hertfordshire Development Centre, Wheathampstead.

This is a flexible one day conference of individual seminar sessions for school leaders, teachers,

governors and parents. Each seminar session lasts an hour and cost £25 per person.

To book a place visit

www.thegrid.org.uk/schoolworkforce/training using reference 07/SEN/001A

Sessions aimed at parent carers include:

Dr Phillipa Russell CBE - Inclusion for severely disabled people.

Jean Salt (former president of NASEN)

Supporting students with special or additional needs and their parents/carers through the transition process into secondary school.

Jenny and Derek Haylock - Grandparenting a child with Aspergers Syndrome.

Jill Adams, The Child Bereavement Trust - Special Needs. Normal Grief

The P.L.A.Y. Project - Play & Language for Autistic Youngsters

This is an effective, affordable play-based autism intervention popular in the USA.

There are 3 workshops over 3 days (3rd to 5th Sept) at St John's College, St Giles, Oxford 10am to 4.30pm

Day 1 focuses on young children (18mths to 7yrs)

Day 2 on High functioning autism

Day 3 is a watch and learn session.

Cost to parents is £45 per day.

For further info or to book a place contact Kathy at Children in Touch on 07780805451 or email

Kathy@childrenintouch.org.uk

Donna Williams - Understanding the Working of Challenging Behaviour.

20th Sept 6.15pm for 6.45 to 8.45pm at the Thames Hall, The King's Centre, Osney Mead, Oxford OX2 OES

Professionals £20, Families & Low income £10

Enquiries: 077 8080 5451 or email

info@autismspeakersandprofessionals.org.uk

Relationships and Asperger Syndrome

A seminar for individuals and couples involved in a relationship where either partner has AS and professionals working in adult support and counselling.

Monday 29th October 07

Venue: RIBA, 66 Portland Place, London W1B 1AD

Speakers are Sarah Kendrickx and Keith Newton the co-authors of *Aspergers Syndrome: A Love Story*.

For more information and to download a booking form go to www.aspergerfoundation.org.uk

Extreme behaviours within ASDs

Tuesday 25th September, The Mostyn Hotel, London.

Speakers include Richard Mills, Director of Research at NAS

Jenny Cutler, Consultant Psychologist, Brookdale Healthcare

Cost: Parents/carers £63 plus vat NAS members who are parents/carers £45 plus vat.

Publications

More and more books are being published on Autism and related conditions which is great news. The NAS has now has some books available to look inside on Google Book Search.

To do so you:

1. click on Google
2. click on More
3. click on Book Search
4. Enter the author, title or The National Autistic Society into the little box that pops up.
5. Hey presto lots of book covers appear and you can click on these and read pages from the books online.

Cutting Edge Publications produce SEN resources for students and teachers. They produce Story Versions; these are simplified and easy to read versions of classic texts such by authors such as Shakespeare and Dickens also Audio CDs and vocabulary cards. They can be contacted by email on mail@cuttingedgepublications.com or phone on 01208 872337 or have a website: www.cuttingedgepublication.com via yahoo.

Different Dads is a new book commissioned by Contact a Family. It consists of a collection of inspiring personal testimonies written by fathers of children with a disability. They reflect on their own experiences and offer advice to other fathers about the challenges of raising a child with a

disability. All royalties from the sale of the book, which costs £12.99, will be donated to Contact a Family. Details from www.jkp.co.uk or 020 7833 2307.

Research Requests

Is there a link between Autism and Testosterone?

Volunteers needed at the Autism Research Centre at Cambridge University.

Our previous studies have found that girls with autistic spectrum conditions are slightly delayed in puberty, and a brief report from France suggests that boys with autistic spectrum conditions enter puberty early. Since the timing of puberty is partly controlled by testosterone levels, we wish to test these levels directly in people with autism.

We are looking for both female and male volunteers with a diagnosis of Asperger Syndrome or High Functioning Autism, aged 18-30. You would need to come to our research centre in Cambridge to donate a small blood sample (similar to the amount that would be taken by your GP).

You will also be asked to do some questionnaires and tests, some on a computer and some in person. In total the study will take around 2-3 hours. You will receive £25 for your participation in our study, as well as full reimbursement for your travel costs.

This project has been approved by the Addenbrooke's Hospital Local Research Ethics Committee. All your personal information will remain confidential. If you are interested or would like any other information, please contact Erin Ingudomnukul via email at personpercept@gmail.com or phone on 01223 746082.

If you are not interested in this study but would like to find out about other projects going on at the ARC, visit our website at:

www.autismresearchcentre.com

Source: Autism Research Centre.

Volunteers needed for London-based autism research

We are interested in hearing from children, adolescents and adults with a diagnosis of autism

or Asperger Syndrome who would like to take part in our research.

At the Institute of Cognitive Neuroscience (University College London), we have an ongoing programme of research with many different projects for people of all ages on the autistic spectrum. This research is led by Prof. Uta Frith, Dr Sarah-Jayne Blakemore and Dr Paul Burgess. The work helps us to better understand why individuals with ASD have particular patterns of strengths and weaknesses. Most of the projects involve paper and pencil or computer tasks, games and stories and we run brain-imaging studies too. Most projects take place at the Institute of Cognitive Neuroscience, Queen Square, London although we sometimes visit people at their homes or schools.

Your personal information will be stored securely and kept confidential. You are free to withdraw from our research at any time. We are flexible about the time of appointments and can see people over more than one session if necessary. You will receive payment for your time and travel expenses will be reimbursed.

If you are interested in taking part or would like further information about our research please contact Dr Sarah White on 020 7679 1168 or email s.white@ucl.ac.uk

Home Schooling

The NAS Communication magazine is planning a feature on home schooling for a future issue of the magazine and would love to hear from Home Schooling families for their experiences for possible inclusion in the piece.

Questions such as why have you chosen to home school? What have been its pitfalls and advantages? Have you been home schooled and what was it like for you.

E mail your experiences to

communication@nas.org.uk with the words home schooling in the subject line or write to The Editor, Communication, NAS, 393 City Rd, London EC1V 1NG. Ensure that you include full contact details including an email address if you have one.

Websites & Online Info

Autism on You Tube

There has been recent criticism of some of the homemade clips featuring autism on You Tube. However there are some more positive examples that help to explain aspects of autism first hand. Firstly - www.youtube.com/watch?v=JnylM1hI2jc The first part draws the viewer into autistic experience and the second uses a computer to explain autistic experience and behaviour to non-autistic viewers.

Secondly -

www.youtube.com/watch?=POIJG3qmV9Q

Here a young boy explains what autism means to people relating to him.

Thirdly - www.youtube.com/watch?v=ic-zA4YfW-U&mode=user&search=

This uses a simple concept to illustrate the range encompassed by the autistic spectrum and the diverse personalities of people with autism.

Source: Umbrella e News May 07

Toys/Equipment/Educational tools & resources

www.difflearn.com

This site has all sorts of learning gadgets, information and ideas for school.

Source: Tracy Oliver - harc member

www.specialneedstoys.com

This site has thousands of toys including some vibrating toys that Lynne Moxon suggested at her sexuality and ASD talks in February and May.

www.fledglings.org.uk

Fledglings is a not-for-profit organisation which helps parents and carers of a child with special needs to find simple, affordable solutions to practical problems. They offer a free product search and supply service for a range of items such as toys, clothing and developmental aids.

www.insidethebubble.co.uk

This website is created by Alice Woolley, a parent of a child with autism. The site has personal insights, links to ABA resources and articles on autism. In particular select 'Articles on autism' then 'Toys and games for autistic children' for advice on choosing gifts for children with autism.

HAVE A GOOD SUMMER!